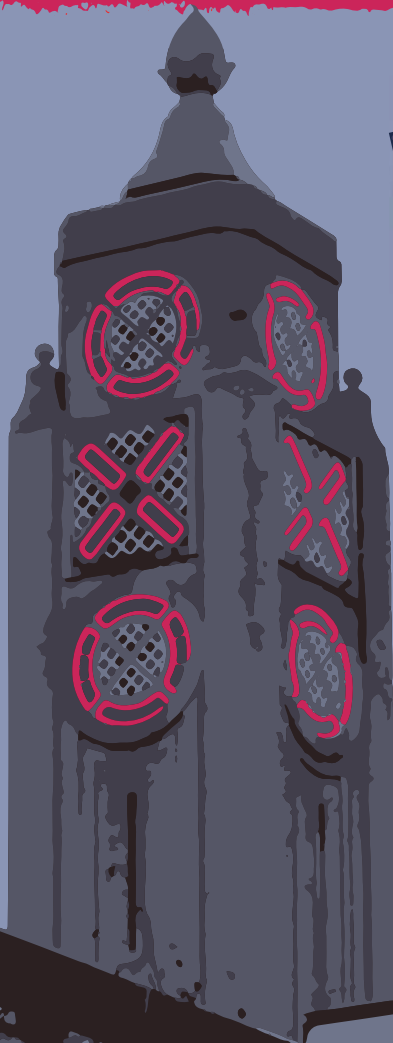


HOW DO YOU C ME NOW?

A sneak preview of the forthcoming exhibition at **gallery@oxo, Oxo Tower Wharf, London** by renowned photographer **Brock Elbank**

P11



P9 Join in with our **Christmas Campaign 2018!**



P12 Exciting new **CMN Conference** planned for 2019



P14 Read about **Teens Big Day Out 2018**



Caring Matters Now

is the only dedicated UK charity supporting those affected by Congenital Melanocytic Naevi

The 3 main aims of the charity are:

- To support those affected by CMN
- To raise awareness about CMN
- To fund CMN research

MEET THE BOARD OF TRUSTEES



There are 7 trustees who are either parents of children affected by CMN or have CMN themselves and so they all have a great desire and are passionate about seeing the charity achieve its aims.

The board of trustees consist of:

- Val Unsworth (*Chair*)
- Ian Chance (*Treasurer*)
- Robert Jackson
- Bronagh Cleland
- Anne McIntyre
- Lucy Hardwidge
- Jodi Whitehouse

Caring Matters Now has three part-time staff who all have specific areas of responsibility. This means the charity functions in a professional manner and ensures not only the smooth running of the charity day-to-day, but also its continual development.



Jodi Whitehouse
Chief Executive Officer



Lucy Hardwidge
Support & Communications Officer



Lisa Sly
Finance & Office Administrator

We encourage all our members and supporters to contact us any time – we are always here to offer support and advice. To contact a member of staff please email:

info@caringmattersnow.co.uk

WELCOME



Welcome to the first edition of your Caring Matters Now magazine!

I am excited to be introducing you to our brand-new publication.... **'INSPIRE'**.

Each year our charity continues to grow and as a result, we have lots of news to share with you! Therefore, the Caring Matters Now board of trustees have decided to produce this attractive and informative 16-page magazine, which includes lots of encouraging and exciting news stories relating to the work of Caring Matters Now and the CMN research. We plan to publish the magazine annually and jam-pack the pages full of news stories to inspire you.

So, grab a cuppa, sit back and enjoy reading through your first edition of **'INSPIRE'**.

Jodi Whitehouse

Jodi Whitehouse
Caring Matters Now Founder & Chief Executive

Don't miss...

- P3 What we do to support you
- P5 Hear how our support helps families
- P7 Research
- P8 Become a **CMN Hero**
- P10 How you've helped
- P11 **'HOW DO YOU C ME NOW'**
- P12 Upcoming Events – **Conference 2019**
- P14 TEENS

CARING MATTERS NOW



Support Contacts



The CMN volunteer support contacts are key to fulfilling our first and most important aim of supporting those affected by CMN.

They are carefully selected to be able to provide you with personalised support. All support contacts are in some way affected by CMN, so have personal experience and knowledge to best advise, support and guide you.

The role of a CMN support contact is to:

- Be available
- Be a friend
- Be a listening ear
- Provide information
- Connect you with other families local to you who are affected by CMN
- Support you in your awareness and fundraising campaigns

Details about your local dedicated support contact can be found on the website:

www.caringmattersnow.co.uk/support/support-contacts/

We invest time and money into our volunteer support contacts by hosting annual training days. During the training days, the support contacts increase their understanding of the CMN research to share with members, share ideas on improving the support offered to our members and receive listening skills training.

Caring Matters Now provides support & information in many ways.....

- Medical Booklet
- Information Leaflet
- Website
- Support Days
- Regional Gatherings
- Teenagers Big Day Out
- Support & Social Gathering for adults affected by CMN
- Social Media Groups
- Specialised Critical and Emergency Support
- Teacher and Parent Packs
- Support Contacts
- Library of Recommended Books



We also collaborate with **Changing Faces** to offer a wider level of support: www.changingfaces.org.uk



Naevus INTERNATIONAL

In early 2018 an exciting global initiative called **Naevus International** was established. This new and exciting international initiative involves a cross-disciplinary partnership between 5 important teams led by Dr Veronica Kinsler:

- 1 Patient support groups** - led by Marjolein van Kessel
- 2 Doctors** - led by Harper Price
- 3 Psychosocial professionals** - led by Béatrice de Reviere
- 4 Scientists** - led by Josep Malveyh
- 5 Communications experts** - led by Jodi Whitehouse

The aims of Naevus International in the first 5 years (2018-2023) are:

- 1** To improve access to, and dissemination of, information about CMN, across and between groups of professionals, patients and families
- 2** To extend the international reach of those groups to include new members in different countries around the world

We are encouraging all our Caring Matters Now members to join the Naevus International mailing list to receive global updates relating to CMN. You can join the mailing list here:

www.naevusinternational.com

THE CMN 7 CHALLENGES ON 7 CONTINENTS ADVENTURE CONTINUES...



Stok Kangri Summit Trek 14th-29th June 2019

- Visit the Tibetan influenced town of Leh
- Ascend one of India's highest Himalayan peaks, 6,114m (219 metres higher than Mount Kilimanjaro!)
- Enjoy spectacular mountain scenery
- Undertake non-technical summit climb

EXPERIENCE A TRIP OF A LIFETIME, WHILST RAISING VITAL FUNDS FOR CARING MATTERS NOW

FOR MORE INFORMATION:



www.caringmattersnow.co.uk



info@caringmattersnow.co.uk

SOFIA'S STORY

Hear Sofia's story and her parents' hopes for her future

On the evening of the 7th July 2017, our beautiful daughter Sofia was born at Liverpool Women's Hospital. I had an uneventful pregnancy and a straightforward birth and we were completely unaware that Sofia was going to be born with a giant CMN. When she was born, the midwife exclaimed that she had a birthmark. I thought 'That's ok!' but I saw my husband's face and I knew it was something unusual. Sofia was born with a bathing trunk naevus that covers the bottom half of her back, wraps around under her belly button and partially covers her buttocks and thighs. I asked if she would be ok and the midwife said yes but that she had only ever seen a baby with this once before. My husband and I naturally 'Googled' Sofia's symptoms and already had an idea she had CMN by the following morning. This was confirmed by the paediatrician, who gave me a sheet he'd downloaded off the internet and told me that she was well and could be taken home, but that the main concern was Sofia developing melanoma in early childhood. My husband had gone to get the car seat at this point, and I sat with my newborn baby and a midwife and cried my eyes out. When we got home, it was difficult telling our eldest daughter about Sofia's condition - I didn't



want her to be scared so I explained that Sofia had been born with a large birthmark and that it wasn't infectious and I encouraged her to touch her skin. She was shocked, but instantly very loving towards her long awaited little sister.

The weeks passed, and we waited for an appointment

at Alder Hey for what felt like an eternity- we had so many questions. In her first few weeks of life, Sofia had blood tests, photographs and an MRI scan. I must have cried solidly for 2 weeks after her birth - my husband held me together. It got to the point where I decided I had to stop crying- my gorgeous little baby was only going to be little for so long and I had to try to enjoy it. We wanted to celebrate the birth of our daughter so we decided to initially keep the news to ourselves (with the exception of grandparents). We also decided not to say anything to anybody because in all honesty, we didn't have a clue what was going on!! We wanted to have the full facts.

I found '**Caring Matters Now**' as a result of researching the condition. Living in Liverpool, we couldn't believe that Jodi (who founded the charity) lived in Liverpool too. I contacted Jodi and a few days later we met her - she has been so supportive and I know Sofia will look

continued overleaf

up to her as she grows up. It was so hard at the start- 'googling' is the worst thing you can do, but also it's natural to be curious. We read about the main 2 complications of giant CMN- neurological and melanoma. We have tried to remain positive that Sofia will be ok and live a full and healthy life and we count our many blessings as she is a lovely baby.



We were referred to Dr Kinsler at GOSH in September and she answered every single question we had. From her MRI scan, Dr Kinsler said that Sofia's spine was clear but that she had one small mole on her brain, but because she isn't showing any adverse effects, Sofia may just have a little developmental delay and will also be seen by a paediatrician once a year until school age. We also found out that Sofia has the rare BRAF gene mutation since she had skin biopsies taken at GOSH. In the new year, we started to gradually tell our closest friends and colleagues and their support has been overwhelming- they have been so supportive and they have been involved in lots of fundraising and promoting the charity. We have also attended a CMN Support Day in Liverpool which was really useful as we could speak to other parents in a

"We are going to teach Sofia to be super proud of herself and encourage her to be resilient"

similar situation to us and know that Sofia will not feel alone. We also got to hear about the research going on at GOSH first hand and we are hopeful that through the research, a breakthrough will be found in terms of treatment. Next month, Sofia is going to have plastic surgery at GOSH because the BRAF mutation has meant that parts of her birthmark are

lumpy, so the plastic surgery team are going to remove five of the nodules and if they don't grow back, the hope is that the others can be removed too. For now, our motto is to be 'positive, proactive and pragmatic' and to try and raise as much money for Caring Matters Now as possible.

Sofia is now 13 months old and behaving as any baby does- she is a really pleasant baby with a gorgeous smile! We are being optimistic about the long-term and we are going to teach Sofia to be super proud of herself and encourage her to be

resilient. If you are reading this as a brand new mum to a child born with CMN, please remember that you didn't do anything wrong in your pregnancy and it was just a chance event.

Try not to worry and get a referral to Dr Kinsler- she is a brilliant doctor.

RESEARCH REPORT

Dear All,

Research update from 2017-2018! Greetings from the whole clinical and laboratory team! We have been busy as usual with CMN research. Your essential funding has been paying for the PhD student **Mr William Baird** (*who is due to finish at the end of December 2018*), the salary of our part-time research coordinator **Mrs Jane White** (*for whom we have obtained alternative funding from 2018*), and continuing to help with the expensive research consumable costs (these are the things we use in the lab for experiments – the science wouldn't happen without them).

This year **Dr Satyamaanasa Polubothu** has been measuring colour change in CMN over time, using standardised measurements of photographs, and this research is about to be published. It found that the colour that a CMN will end up is related to the person's own pigmentation, so that lighter haired or red haired people with lighter skin will end up with a much lighter coloured CMN than people with darker hair and skin. The final colour is not however in any way related to the colour at birth, which is usually very dark, and is probably influenced by maternal hormones. In addition, we found that laser therapy and dermabrasion and curettage therapy (all forms of removing the top of the CMN) do not alter the final colour in the long term as pigment grows back to the colour it would have been anyway. Dr Polubothu has also been doing work looking for new genetic causes of CMN, and identified the gene BRAF as a rarer cause of CMN than the one we know about already (NRAS). Another group published one case of this before us, and we will be publishing our seven cases shortly. The hunt for the genes in those where it is not NRAS or BRAF is continuing and thank you to everyone who has helped with this. During the last year, **Ms Lara Al-Olabi** (*who has now left the group to return home*) and **Dr Melissa Riachi** (*a new post-doc in our lab*) have been working on the genetics of patches of normal skin appearing inside CMN. A few very brave patients with this rare happening have been incredibly generous in giving skin biopsies to allow us to learn for the good of all patients. The findings are very exciting and important for future genetic treatments, which are the focus of Mr William Baird's PhD thesis. That work will be published at some point in 2018 we expect, with William's work being continued by other lab members into 2019.

Another important publication in the last year was an important review of all our melanoma cases, with recommendations for monitoring and management of melanoma arising in CMN patients.

We would like to thank you all for your fantastic fundraising, and for continuing to help us in CMN research. We could not do it without your participation.

Veronica Kinster



Great Ormond St Hospital and the UCL GOS Institute of Child Health
August 2018

CMN Hero

Monthly Giving & Payroll Giving

DOWNLOAD
THE CMN
FUNDRAISING
TOOLKIT

[www.caringmattersnow.co.uk
/get-involved/
fundraising-toolkit/](http://www.caringmattersnow.co.uk/get-involved/fundraising-toolkit/)



Become a CMN Hero by supporting Caring Matters Now! You don't need to challenge yourself in anyway, you don't even need to leave your sofa, just choose one of the following suggestions. By choosing to do even just one of the following will make a big difference to the lives of those with CMN!

Will you become a CMN Hero?

To sustain the support we offer, the research we fund and the awareness we raise, Caring Matters Now must raise a minimum of **£100,000 every year**. The CMN trustees are keen to increase our monthly giving to help us reach our annual fundraising target. Monthly giving provides the charity with sustainable regular income and enables the trustees to manage how funds are spent in a more strategic way.



- **79p** of every **£1** you raise goes on our charitable objectives - support, awareness and research.
- **21p** is spent on development, governance and work to increase funds

There has been a significant increase in monthly donors over the past 4 years. In 2015 we had 18 donors with a total of £237 per month. With huge thanks to our CMN Heroes we now have 36 monthly donors with a committed **£853.75 per month**.

What does your donation buy?



£10 a month
donation will pay for a child to attend the CMN confidence building weekend



£8 a month
donation will pay for the publication of 200 CMN medical booklets to distribute to doctors across the UK



£40 a month
will buy a full investigation of the genetics of a patient with melanoma

Corporate Partnerships

Could your workplace become a Corporate Partner with Caring Matters Now?

Charity of the Year – please consider adopting Caring Matters Now as your charity of the year by asking your employers and staff to fundraise for us.

Corporate Charity Challenges – Caring Matters Now is working in partnership with Charity Challenge to offer companies a unique opportunity to improve company success, whilst demonstrating great Corporate Social Responsibility. Whatever your profession, improving the dynamics of your staff will have a big impact on the success of your business. Caring Matters Now is offering companies a once-in-a-life time experience for employees through CMN Challenges.

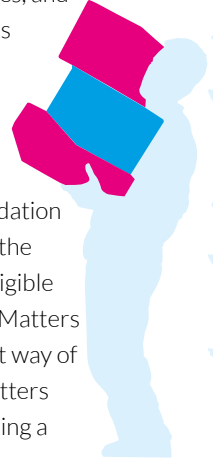
Take a look at the website for more details

www.caringmattersnow.co.uk/get-involved/our-partners/partnerships/

The Amazon Smile logo, featuring the word "amazon" in black and "smile" in orange, with a yellow curved arrow underneath.

If you are an Amazon shopper then consider using **AmazonSmile** (smile.amazon.com). This is a website operated by Amazon with the same products, prices, and shopping features as **amazon.com**.

The difference is, when you shop on AmazonSmile, the AmazonSmile Foundation will donate 0.5% of the purchase price of eligible products to Caring Matters Now! This is a smart way of giving to Caring Matters Now without spending a penny more!



Christmas is coming... CHRISTMAS CAMPAIGN 2018

Instead of buying unwanted gifts such as socks or sweets, hankies or hand lotion, why not donate the gift amount to **Caring Matters Now?**

In return you will receive a Christmas gift voucher for the amount you donate, which you can then send on to your family member or friend.

By donating a gift of £25 or more, you will receive a gift bundle along with your gift voucher! The gift bundle will include a CMN lunch bag, pen, lanyard plus information about how your gift donation is making a difference to our charity.

www.caringmattersnow.co.uk/caring-matters-now-christmas-gift/

FABULOUS FUNDRAISERS



On an overcast day in June I held a brunch to raise funds for CMN as my beautiful granddaughter Sophie has this condition.

About 35 friends and acquaintances attended and all were happy to start the occasion with one or two glasses of prosecco.

Sophie behaved beautifully and with her infectious smiles and giggles brought the sun out. She enjoyed being cuddled by everyone and it certainly was a happy occasion that helped raise much needed funds for the charity.

NEW YORK WINNER!

Huge congratulations Vicky on winning the two return flights to New York.

On contacting Vicky and announcing that she is the winner she responded -

"Our son has CMN covering his entire back and since he was born 3½ years ago we were immediately introduced to Caring Matters Now. A large amount of the information we have received is via the charity and their financial support to Dr Kinsler to research the condition is invaluable.

I recently got engaged and was hoping to win so myself and my fiancé can have our honeymoon there as it's the first place we went on holiday



Such an emotional night last night at the final night, **#showtime2018**. It has been an amazing week to be a part of, watching my little ladies up on stage all week showing such confidence. I felt so proud of them. The show has been fantastic, so much hard work and talent up on stage, you do an absolutely amazing job Sarah!

We are absolutely overwhelmed with the amount that has been raised by Sarah Patrick, all the cast, parents, audience, sponsors, etc. throughout the week. Funds raised support those children and parents affected by CMN, raise more awareness of CMN & continue to drive further research. From the bottom of my heart

Thank you, Thank you, Thank you xxx

together making it extra special! I can't believe it! Thank you so much!

I am thrilled to have won and will continue to support Caring Matters Now!"

We are delighted for you Vicky -

congratulations!

From all the CMN Trustees we would like to take this opportunity to thank everyone who contributed to this fundraising raffle raising a substantial **£1,251.**

AWARENESS

'HOW DO YOU CME NOW?' exhibition launch dates confirmed!

Over the past 24 months, the CMN trustees have been working in partnership with the world-renowned photographer **Brock Elbank** to create a series of stunning portrait images of children and adults from across the world, affected by CMN. The series includes all ages, both male and female, with 13 countries represented, making this series uniquely special. The countries represented are as follows: **Norway, Switzerland, Australia, Poland, UK, Sweden, Spain, France, Italy, USA, Ukraine, Brazil** and **China**.

The aim of the exhibition series is to give a clear message to the world - to love the skin you are in! We want this beautiful series of images to reduce the public's negative perceptions of visible differences, as well as raising positive awareness of CMN.

The title of the exhibition series is 'HOW DO YOU **CME NOW**?' The title poses a question, seeking individuals to consider their current perceptions and views of individuals living with a visible difference. The exhibition title will encourage the general public to look twice at the images and consider what their eyes were drawn to first; the visible difference (CMN) or the beauty of the individual? We hope the public will consider the beauty of the individual *because* of their CMN and not in spite of their CMN.

The trustees are excited to announce that the exhibition launch event and 12-day exhibition will be at the prestigious Oxo Tower Wharf on the South Bank in London. Oxo Tower Wharf is an award-winning, landmark building situated on the riverside walkway, part of London's fast moving South

Bank and Bankside areas. Oxo Tower Wharf is home to some of the UK's most innovative and internationally renowned contemporary designers, restaurants, cafes, bars and exhibition venues.

The exhibition will be open to the general public from Wednesday 13th March - Sunday 24th March 2019. We expect high volumes of visitors during the 12-day exhibition, as the average daily footfall passing by the gallery is 3000!

Once the launch has taken place in the UK, we plan to exhibit the series in countries across the globe over the next 2 years.

This is the biggest project Caring Matters Now has ever undertaken with regards to raising awareness of CMN. The CMN trustees believe the exhibition series has huge potential to raise global positive awareness of CMN. Brock Elbank's previous series was exhibited at Somerset House in London and he received over **£1.6 million** worth of press exposure! This gives you an idea of the huge opportunity this exhibition has to raise the profile of CMN and Caring Matters Now.

We will be releasing further details of this fantastic exhibition series at the beginning of 2019.

If anyone can offer assistance with seeking corporate sponsorship, please do get in touch jodi@caringmattersnow.co.uk. Please share the information once released with all your family, friends and social media followers! We want as many people to access the exhibition as possible. Here's to a fantastic 12 months of raising positive awareness of CMN on a global scale!

YOU ARE INVITED TO THE FIRST EVER CARING MATTERS NOW CONFERENCE!



We are very excited to invite all our members to the first ever **Caring Matters Now Conference**, taking place **5th-7th July 2019** at the Liddington PGL Conference Centre.

Our weekend conference is going to be cram-packed full of activities which will cater for everyone! We have planned specific activities for our adult members, teens, children and parents, including lots of fun outdoor pursuit activities; psycho-social presentations and workshops; CMN research presentations including Q & A session with the CMN research team - and much more!

This weekend conference is not to be missed and we want to help all our members attend. Therefore, as an early bird offer, Caring Matters Now will cover the cost for each person affected by CMN to attend the conference. We hope this support will enable more members and families to attend.

- ★ Meet the research team
- ★ Activities for teens
- ★ Activities for kids
- ★ Events for Adults with CMN
- ★ Presentations
- ★ Psychology lead workshops

Costs

£150 per person (age 4+)

Early Bird Offer

Take advantage of the Early Bird Offer by booking before **1st December 2018** to receive your **FREE** place for the individual affected by CMN.

Accommodation

The accommodation consists of family rooms of multi-bedded bunk beds.

Booking & Deposits

Please complete the booking form available on our website at: [www.caringmattersnow.co.uk/2019-caring-matters-](http://www.caringmattersnow.co.uk/2019-caring-matters-now-conference/)

now-conference/

We require a £35 deposit for each individual when you book. Full balance must be paid 8 weeks prior to the weekend conference. A detailed conference schedule will be made available early 2019.

We look forward to seeing you there!



CMN Merchandise



Why not consider purchasing some of our CMN merchandise as gifts this year for your loved ones?

Take a look on our website at our collection:

www.caringmattersnow.co.uk/merchandise/

HAVE YOU RE-REGISTERED YET?

GDPR, which stands for General Data Protection Regulation, is the biggest change to UK data privacy law in 20 years and it came into effect on 25th May 2018.

To ensure we continue to be fully compliant with the new GDPR legislations and to ensure we can still keep in touch with you, we require everyone to re-register with us. If you have already re-registered, thank you for doing so! If you are still to re-register:

If you are an adult affected by CMN or parents of a child affected by CMN and still need to re-register, please go to:

www.caringmattersnow.co.uk/support/membership/

Friends of Caring Matters Now (*grandparents, aunts, uncles, friends, donors, fundraisers, schools, corporate sponsors*) please go to: www.caringmattersnow.co.uk/get-involved/keep-in-touch/

For more information visit: www.caringmattersnow.co.uk/gdpr/

The right to be forgotten

Every individual has the right to be 'forgotten' online. As a charity we ensure written consent is given for all images used in our marketing materials, on our website and on our social media platforms. If at any point you would like your image, or the image of your family member to be removed from our marketing materials and online platforms, please do contact us and we will remove the images with immediate effect. For more information regarding your right to be forgotten please contact info@carimgmattersnow.co.uk

Please do take a look on our website or our social media platforms to ensure you are still happy for us to feature any images of you.



CMN YOUTH

teenage@caringmattersnow.co.uk

In this section of the CMN magazine **INSPIRE**, you will find all the interesting stuff for our youth! We hope our younger members find these few pages helpful in bringing together our youth community. This section is for you guys, so keep in touch and share your stories, experiences and news! You can contact our Youth Support Contact, Katie anytime by emailing teenage@caringmattersnow.co.uk

Teens Big Day Out 2018

SATURDAY 13TH OCTOBER 2018

Go Ape! Battersea Park, London.



High ropes, low ropes - whatever takes your fancy - but be there!

Join us for what promises to be a great team building and social gathering for all those affected by CMN aged 11yrs – 17yrs.

More details on the website: www.caringmattersnow.co.uk/teens-big-day/

Book now: www.caringmattersnow.co.uk/support-event-attendance-registration-form/

Jasmin's story

As a teenager with CMN, I have been through a lot, including name calling and mimicking. My CMN is located on my nose and right cheek. I had my first of 6 operations at 8 months of age at Great Ormond Street Hospital, all performed by the wonderful Mr Bulstrode.

I first attended a Caring Matters Now family day at 4 years of age, this was a great relief for my parents to find other people in the same position as us. Caring Matters Now have given me and my parents' great support and are like a family to us now.

The support days are great fun for the children and adults to socialize with other families and charity helpers and trustees. As a result of the family days, my Mum is now London support contact and my dad is the charity treasurer and also a trustee.

As a family, we attend the London support day with my younger brother Alex too, an event I personally really enjoy attending and helping at. A couple of years ago, I felt that I wanted to get more involved, so I asked Jodi if I could say a few words at the London support day about my experiences and explaining how I cope with having CMN. Speaking at the support day has given me self-confidence and helped me with my public speaking, which is an important skill in life.

I would encourage everyone to share their experiences at the CMN support day. Just speaking one-to-one to other children who are there, particularly those who are attending the event for the first time, because it might help others who are in a similar position to you, and it can help you to grow in confidence too.

If you'd like more details about how you can get more involved in the support days as you get older, please get in touch with the Caring Matters Now teenage support contact, Katie Arends at teenage@caringmattersnow.co.uk

It would also be great to chat more regularly with Caring Matters Now teenage members, so if you would like to be in touch you can contact me on my Mum or Dad's email addresses which are ian@caringmattersnow.co.uk or michelle@caringmattersnow.co.uk. I look forward to hopefully hearing from you soon and seeing you at the next London support day event.

Jasmin Chance



My story by Ryan (with a little help from mum)

I was born on the 10th December 2003 with CMN and NCM. My birthmark covers my bum and I have hundreds of smaller moles all over my body. The moles on my brain also cause me to have learning disabilities and I also have ASD. I have difficulty with my working memory and this gets really frustrating for me.

I've always been a water baby! I hated playing with toys when I was younger, as I always preferred to splash with water or tip water in the sink! When I was 8 years old my mum took me swimming and I loved it! I used to get lots of stares and people would say nasty things about my skin but this only made me stronger and I wanted to prove to people that I could swim. I joined a swim team and began to train twice a week. I managed to get my 25 metre badge when I was 9! I carried on trying hard and not letting my health issue get me down. I spent a lot of time in hospital, but always bounced back.

Last year I was bitten by a tick and this caused me to become really poorly. I'm a lot better now after a long course of medication but I have been left with another illness called chronic idiopathic urticarial. This illness causes my skin to itch all over and I get a red burning rash. Unfortunately, temperature change triggers this off and as I get hot during swim training, I sometimes get the rash all over which effects my training but I won't let



it stop me.

I am now 14 and train 6 times a week. Recently I have been selected to represent England on the para swimming talent programme. I compete in the S 14 category which is for swimmers with an intellectual disability. I recently won the junior nationals 100m backstroke and gained 3 silvers in other events.

I have two major competitions coming up this year which I am training hard for. This means I have to get up at 4am in the morning to get to the pool for 5am start! I am the youngest member of my swim training group and also the only one with CMN. Sometimes it's hard for me as people still stare at me especially when I have my swimming trunks on, but it's boring to look

normal and I like to be different.

There is a big competition coming up next year in Brisbane Australia, which I am aiming to get selected for. The competition is

called the Global Games. This is just an event for elite athletes with learning disabilities. I can't wait to swim and represent GB.

My aim is to get to the Paralympics when I'm older and I'll try my very best to get there!

I wanted to share my story to hopefully inspire other kids with CMN/NCM. Nothing is impossible if you want to achieve!

Follow your dreams and don't let others get in your way.

"I have the power within me to overcome any and all adversity and nothing or no one can slow me down or hold me back... I am unstoppable"

THANK YOU FOR ALL YOU DO!

We have found the cause... now it's time to find the cure!



We couldn't do what we do without your continued support.



Caring Matters Now relies entirely on the generous support and fundraising of our members, friends and families to allow us to inform and support those affected. The funds so kindly donated make a huge difference to the lives of those affected by CMN syndrome.

If you know someone who you think may like to support the work that we do, then why not give them your copy of this magazine so they can see what we do and why.

Share our online donation page:

www.justgiving.com/caringmattersnow

If you would like more copies please email us:

info@caringmattersnow.co.uk

If you would like further information about how you can support the work of **Caring Matters Now** or have questions, feel free to contact us:

✉ **Caring Matters Now** | PO Box 732 | Cambridge | CB1 0QF

☎ 07786 458883 @ info@caringmattersnow.co.uk 🌐 www.caringmattersnow.co.uk

Registered Charity No: 1120988